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MEETING THE PRESENT AND FUTURE NEEDS FOR LONG-TERM CARE

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JERSEY CITY, N.J.

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FEBRUARY 27, 1984

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Jersey City, N.J.

The committee met, pursuant to notice, at 10:36 a.m., at Jersey City State College, Jersey City, N.J., Hon. Bill Bradley presiding.
Present: Senator Bill Bradley.

OPENING STATEMENT BY SENATOR BILL BRADLEY, PRESIDING

Senator BRADLEY. The hearing will come to order. The Senate Aging Committee is pleased to hold a hearing today at Jersey City State College on the issue of long-term health care. The committee is conducting a hearing in New Jersey to gather information on how we can best meet the long-term care needs of this Nation's elderly. I know that all of you share my deep concern about how we can assure our senior citizens the care they require.

Long-term care is a problem for many elderly today, and it will be a problem for many more elderly in the years ahead. By the year 2000, the over-85 population in this country will be 60 percent larger than it is today. And 15 million individuals 65 years and older are expected to suffer chronic disease that will limit their daily activities in the year 2000, a 50-percent increase over 1980.

These figures illustrate our future needs for long-term care. But already we are unable to keep pace with our growing elderly population. A recent Government study reported that in 1977 only 50 percent of the people classified as severely dependent lived in nursing homes. The number of chronically ill elderly living in the community are estimated to be up to three times as great as the number living in nursing homes. Many of these people are not receiving even the most rudimentary assistance.

Of those who are in nursing homes, many live in an isolated and sterile environment and are deprived of their personal independence and dignity. They are forced into institutions because they have no alternative. I am not opposed to nursing homes. On the contrary, for many elderly citizens, nursing homes offer the most appropriate and comfortable care. But nursing homes are not the answer to the long-term needs of all of our senior citizens.

First, nursing homes are expensive. Between 1965 and 1985, the cost of nursing home care will have quadrupled. At least one-third of the people who initially pay for their own care become eligible for medicaid in less than 1 year after admission to nursing homes

because their care has eaten up all their assets. Second, I am convinced that, in many cases, life would be a lot better for elderly people if this country developed a more extensive program to provide long-term medical and social services in their own homes.

I would like to take this opportunity to mention legislation that I am cosponsoring that I hope will help us meet some of the long-term care needs of this Nation's elderly. My bill, S. 1244, the Senior Citizens Independent Community Care Act, is designed to assist medicare patients age 65 or older to avoid placement in a nursing home, unless it is medically necessary. The bill specifically targets the high-risk elderly, those who need home services in order to avoid placement in a nursing home. People eligible under this program would receive all medicare part A and B services and several new services, including homemaker home health aides, adult day care, and respite care. Participants would receive an individual assessment and treatment plan, and their services would be coordinated. The bill provides for a 4-year demonstration in not more than four States. Obviously, I would hope and expect New Jersey to be one of those States.

I also am cosponsoring a bill that would coordinate medicare and medicaid resources and would expand the home and community services for those individuals who are eligible for both medicare and medicaid benefits. The Senate Finance Committee held hearings on these two bills, and I hope to see Congress take action on them in the near future.

The Federal Government has a responsibility to develop innovative ways to meet the long-term care needs of this Nation's elderly. And I believe that these two bills are a step in the right direction. But these are problems that need to be addressed at every level, by State and local governments, by the private sector, by health care providers, and by private citizens. As I hope we shall see this morning, efforts are being made at all these levels. We need to continue those efforts, we need to work together and we need to hear from people, like many of you in the audience who deal directly with problems of long-term care, as service providers, as family members, and as senior citizens.

For the hearing, we will have two panels of witnesses. Following the formal testimony and the closure of the hearing, I will invite individuals in the audience to ask questions or make comments.

I want to welcome our first panel today, who I think can offer unique perspectives on this problem of long-term care. Let me thank you for coming today and introduce you to the committee. Mary Rappaport of Medford, Frank Gerne of Jersey City, Marion Stiles of Medford, Ann Charnowitz of Jersey City, Mary Bongiovanni of Jersey City, Raymond Branagan of Bayonne, and Vivian Thomas, a homemaker home health aide from Paterson, N.J.

Let me welcome you to the hearing, and let me ask you to each make a short statement and try to keep it under a couple of minutes. Then we will get to a series of questions that I would like to ask you. Let me also ask that when you speak, please speak into the microphone so that everyone in the room can hear you. If you need any assistance, we will be pleased to provide that for you.

Welcome to this Aging Committee hearing. Let us begin by hearing first from Mary Rappaport. Thank you so much for coming.

STATEMENT OF MARY RAPPAPORT, MEDFORD, N.J.

Ms. RAPPAPORT. I am very glad to be here. I come from Medford Leas, N.J., where we have a retirement community which is really fabulous, as far as I am concerned. It is in a lovely setting and we have good food. We have wonderful medical care, and if I had not gone there, I would be financially broke, because I could not have kept up with all of my hospital costs. I could not have kept up with all the treatments, radiation, and what have you, because I happen to have nymphomia, which is a form of cancer.

I have gone to the hospital repeatedly and they had to give me X-rays. They have given me radiation for total hip. I had total hip replacement because the bone there had deteriorated. Then later, they found there was a growth on my spine and I had to have radiation once again. And then they found that my shoulder was fractured because the bone had deteriorated, so again they had to take care of me through radiation.

I have also had chemotherapy and I have had many treatments. I have been transported back and forth to the hospital time and time again and each time Medford Leas took care of it. So you can see why I am glad that I am in a retirement community. If I had not been there, I would have been a burden to my brother, who lives in Evansville, Ill., or my sister, who is in Scottsdale, Ariz.

With that I will say I will be open to any questions you would like to ask me.

Senator BRADLEY. Thank you very much, Mary Rappaport. Let us just go down the row. Raymond Branagan, please take the microphone.

STATEMENT OF RAYMOND BRANAGAN, BAYONNE, N.J.

Mr. BRANAGAN. Thank you, Senator. I take care of my mother. She is 94 years of age this coming April. In December 1959, my mother broke her right hip and she was operated on unsuccessfully because bone absorption prevented the pin from holding. After that it went from one thing to another, arthritis, crutches, to a walker, then a wheelchair. With the help of her brother, who has since passed away, and good neighbors, and after hospital stays, with limited help of a visiting nurse and home health care services, we got by until November 1983, when my mother's other hip developed a hairline crack causing pain and another visit to the hospital.

When she got home, we got help from the visiting nurses, therapists, a home health aide, which now, unfortunately, will terminate the end of this week. My mother is now confined to bed, which is very difficult for me, being a man, to handle since she must use a bedpan and requires frequent bathing, which I cannot do. I myself am 72 years of age and I am under treatment for a heart condition.

We have attempted to get help from title XX, and the answer I got there was that they have no funds and a long waiting list. Medicaid, we applied for. My mother seems to have too much income for medicaid, but too little to pay for private help. Her savings are exhausted and she is on a very limited income, only from social security, and a small pension from my father's railroad retirement.

From here I do not know where to go.

Senator BRADLEY. Thank you very much, Mr. Branagan. We are going to hear from everyone and then we will get to questions. Ann Charnowitz.

STATEMENT OF ANN CHARNOWITZ, JERSEY CITY, N.J.

Ms. CHARNOWITZ. My name is Ann Charnowitz, and I have a sister that has Parkinson. When she was in the hospital—she was there 4 or 5 weeks at different intervals—I always had a homemaker. But now I am starting to get arthritis and I cannot take care of her. I wanted a homemaker only recently, December 23. A doctor gave the nurse a note, but medicare will not pay for it. So I am out of luck. I just cannot cope with the situation. I need somebody to take care of her. I have been doing it all alone.

She is in and out of the hospital frequently with the Parkinson. As she comes into the hospital, they take care of her there; when she comes out, I always had a homemaker. In the last year or so, I have not had a homemaker. I have to take care of her myself. And it is very bad for me. I have arthritis in the neck, all the way down the arm. I have to give her a bedpan. I have to take care of her. I wash her, I clean her, which I do not mind doing. But now I have this arthritis and I cannot do it. So I think the homemaker service should really be reinstated and whoever needs it should get it.

Senator BRADLEY. Thank you very much. Mary Bongiovanni.

Ms. BONGIOVANNI. Thank you, Senator. Please forgive me if I am a little shaky.

Senator BRADLEY. You should relax and know that we are all here to hear what you and the others have to say.

STATEMENT OF MARY BONGIOVANNI, JERSEY CITY, N.J.

Ms. BONGIOVANNI. This is a very difficult time for me because my mother passed away at the age of 91, last Wednesday, and the funeral was Saturday. We received wonderful care from the visiting nurses, the homemakers, the doctors, everyone who was concerned with her care for the past year has been wonderful. But the home care has been cut back gradually to less and less. My mother lived alone. She would not go with anyone. She has five daughters and a son. She wanted to spend the rest of her days in her own home. There were five family members who lived further away than I do, but they all helped. They all had their own families, but we could not get help for more than 2 hours a day, 3 days a week, up until the last time, and that was going to be taken away. My mother prayed to pass away so that we would not have to be burdened, plus she saw how the cutbacks were coming. She had all her faculties right to the last moment, and it was sad because she was sad about what her children had to do. We are all senior citizens, her children. So we are not young. We all have ailments of our own. Everyone helped as much as they could.

I think that it would be nice to provide help for other people in situations like that who have less help than my mother had. We were able, thank God, and thanks to all the outside help, we were able to keep her in her home till the end. She was in and out of the hospital for 1 year. And at home she did have care, good care, but less and less as time went on.

I am here to help the ones that remain so that they can get help when they need it, the people that are alone and have no one. My mother's funds are exhausted, but we were willing to contribute and we did as much as we could. I am sorry for the ones that have no one, they are the ones I am here for. Thank you very much. I cannot go on.

Senator BRADLEY. Thank you very much. Marion Stiles.

STATEMENT OF MARION STILES, MEDFORD, N.J.

Ms. STILES. I am not ill; it is my husband. He has Alzheimer's disease. About 6 years ago he started with Alzheimer's disease. We owned our own business. He ran the office, which meant writing out the orders, doing income tax, government reports and all of that. The first thing we noticed was he could not add and subtract correctly, either mentally or with machines. He continued doing this office work and my brother and I checked all of his figures and kept things straightened out.

At that time, it was necessary for him to go out to the mill to work on filling the orders. This meant that he had to read the order slip and fill the trucks with the right kind of feed. Soon customers were coming back because they had gotten cracked corn instead of horse feed, and so forth. After a year of this, he had to stop work completely.

We lived at home, and I tried to keep him busy with gardening, with mowing grass, hammering nails into a board, anything that would keep him occupied. He kept running away, crossing our busy main street and going back to the mill to work. So I had to bring him back and watch him all the time, 24 hours a day. I was doing this for 1 year.

You talk about homemakers. They are very difficult to depend on. They do not show up. Doctors will not come to the house. It is very difficult to take care of someone at home like that. So we moved to Medford Leas. There we lived together in an apartment for 2½ years. I had home health aides who could come at any moment. And they came many times to help me out. My biggest help was from the occupational therapists. They would take him for an hour, sometimes 2 hours every day except Sunday. They did exercises, cooking, handwork, all types of things.

Six months ago, Labor Day, he became so hyper I could not manage him in the apartment, so he was transferred into a high skilled nursing area. They found that I could not give him the care that he needed for 24 hours every day, so he is now in the medical area. He likes to walk and I can go in there at any time and walk him all over the grounds, take him back to the apartment and have lunch, but his home was the medical area; from the time he went there, I never had to ask him to go back.

Then he had a fall about 2 months ago. This fall did a lot of brain damage and so now he is a bed patient. He was in the hospital for 3 weeks. Now he is back at Medford Leas getting lots of tender loving care. I can go see him and stay as long as I want every day.

I still have my apartment. Living at Medford Leas helped to keep my sanity. We have a swimming pool and I go swimming every

morning to get rid of tension. They do those horrible medicare forms, Blue Cross forms. They take care of all of his care and the residents are very wonderful. The keep me very busy with invitations and things. Living at Medford Leas has been a godsend to me. I just could not have done this without it.

Senator BRADLEY. Thank you very much. Frank Gerne.

STATEMENT OF FRANK GERNE, JERSEY CITY, N.J.

Mr. GERNE. Your Honor, let me bring you back 5 years. My wife was brought into the hospital with a rare blood disease. In other words, the blood was not getting enough oxygen. Now the doctors and staff at the hospital saved her life. That was 5 years ago. She is completely incapacitated in a wheelchair now with arthritis in her legs and her hands.

During that time I waited on her. We had help from the medicare people and the hospital. Since then, I developed Parkinson's disease, which is encroaching on me continuously. I lost my speech and my ability to mobilize myself in this condition. We are both 76 years of age. They cut back on my senior citizens assistance. Took my therapist away.

In order to make this presentation at this time, I had to get up at 6 in the morning to dress properly and make an appearance down here. I am sorry. I cannot go on anymore.

Senator BRADLEY. Thank you very much for coming and for making your statement. I and the committee really appreciate it.

And now, Vivian Thomas is our last panelist.

STATEMENT OF VIVIAN THOMAS, PATERSON, N.J.

Ms. THOMAS. Thank you for inviting me. I come from the visiting homemaker-home health aide agency. I am a health home aide, and I have been trained to go into homes to take care of the sick and paralyzed; some have arthritis, and some of the patients need more care than medicare allows.

I have been with the agency about 5 years. I have been in this case that I am working on now for 4 years. They needed about 7 hours when I first went there, but I was there 4. We are assisted by a registered nurse to supervise us on the cases. Also therapists. If the patient needs a speech therapist, we have that, too. Some of the patients need more time.

For instance, I teach patients that had a stroke, teach them to walk. I work 5 days a week. By the time I finish, in the 2 days, the work that I have done has been taken away. Some of my patients have a companion and some are alone. The people that are alone need someone more than the 2 or 3 hours that medicare pays.

This is what I am here for, to see if those that need it can get more help than the 4 hours a day.

Senator BRADLEY. Thank you very much. Let me ask all the panel a series of questions and then each of you can respond.

Some of you have talked about your own family. Now, you have had a family member who has chosen to stay in his or her home as opposed to going into a nursing home. What is the reason leading to that decision? Was it a question of just the quality of life that

made them prefer to stay in their homes? Or was the cost a real problem as well?

Mr. BRANAGAN. I would say to a great extent, with my mother, she always loved her home. She never wanted to leave it. In fact, right now she does not live with me, she lives alone. In the same apartment building, but in a different apartment.

Senator BRADLEY. And she is 94 years old?

Mr. BRANAGAN. Yes; 94 years old. Her faculties are very good mentally. Of course, physically she is just detericrating. And I think that is the whole thing. She at times feels bad and at times she cries sometimes when I take care of her, that I should have to do this because her being a woman and me a man. But on the other hand, she does say, "I think I should go to a nursing home, because I do not want to bother you this way." But I do not want to leave her. I know it would break my heart to send her to a nursing home because I know it would kill her right away. She loves her home and she is particular. If something on the table is in the wrong place, she will tell me, "Put it where it belongs."

Senator BRADLEY. Just like she always did.

Mr. BRANAGAN. Exactly. I think that is the major factor. Of course, financially, that is a big thing, too. There is another thing I did not bring out when I spoke before. I have a heart condition myself and God forbid, if something happens to me, where does she go? I have inquired about nursing homes just in case something did happen. It seems that there is a waiting list there too. The cost is prohibitive. You cannot touch the price of it.

Senator BRADLEY. I guess both factors are important.

Mr. BRANAGAN. I would say so.

Ms. RAPPAPORT. I would like to say that if my brother had to take care of me, or my sister had to take care of me, that would not please me at all. It would make me very, very unhappy. I would not want to be a burden to him, and I certainly would not want to be a burden to my sister.

Also, I have to say something about what I have gone through. I have been 18 months at the convalescent home. Many think of it as an infirmary, but we call it a convalescent home. And I have been 18 months where we have intermediate nursing and I have now recovered to the extent where last Friday, I was able to go in our swimming pool and swim on a side stroke five times around the pool. And then on my back I was able to go four times around the pool. I never would have been able to do this, if I had not been where I am now.

Senator BRADLEY. I think you ought to think about Olympic swimming. Ann Charnowitz.

Ms. CHARNOWITZ. I think Mr. Branagan said it very nicely, and personally I think human beings that have any kind of disease are more relaxed in their home. They feel better. They feel that this is their home. If they go among strangers, they do not feel as well as they would when they are in their own house. That is the way I feel about it.

Of course, taking care of a sick person is not pleasant, but on the whole, at least you have them home. At least you know that they are there. And at least you know what they are thinking. And at

the same time you feel, well, thank God they are alive. That is the way I look at it.

Senator BRADLEY. Let me ask the three of you who cared for someone in a home setting. What specific services do you think would be of great benefit to you in trying to care for your loved ones in a home setting?

Ms. CHARNOWITZ. You take me, for instance. I have never had arthritis, but now all of a sudden I have got it. I could have a little help, whichever person they are sending from the homemaker service, to wash and dress her and feed her for as many hours as they give. I do not know what they do today, but they did give 4 or 5 or 6 hours. And she did have a physical therapist. She could use that, too. I feel that medicare should supply it.

Senator BRADLEY. So essentially homemaker aides and physical therapists would be helpful. Ray or Mary?

Mr. BRANAGAN. I would say much the same thing about what would be beneficial help for me right now. The service that I have been getting since my mother was last in the hospital, which was in November, has been limited to 2 hours a day, 3 days a week. Now, what this means is that the homemaker, when she comes, really has to move along to be able to give her bath, change the bed, dress her, wash her, and so on. A little longer time would be very helpful. In fact, more than 3 days a week, to me, would be helpful. Because I too have a life to live and I am definitely confined to one spot. I probably have 2 or 3 hours in between each session, such as getting up, dinner time, and going to bed, where it would be a big help to me as well as my mother, if I could have help a little bit more than I have been getting.

Senator BRADLEY. Ms. Stiles, is there anything in particular in ygur case that would have been helpful, given Alzheimer's disease?

Ms. STILES. Maybe this is not on the subject, but my husband and I talked this over many years ago. My mother-in-law came to live with us when we were married 1 week, and lived with us for many, many years. We decided then we would never put this burden on anyone in our family. So when they started building Medford Leas, we immediately put our name on the list, so it would not happen in our case. It was hard giving up our home.

Senator BRADLEY. So in your case, you felt that being in a community that was a full service community——

Ms. STILES. Served our needs.

Senator BRADLEY. And you took advantage and reserved the place prior to having to make a choice between your home or a nursing home.

Ms. STILES. It was in our hometown. We did not have to leave our community. This was a great asset.

Ms. BONGIOVANNI. In our particular case, my mother, being up in years at 92 and foreign born, Italian, raised us basically family-oriented. She became very modern in many ways, in many of her ideas, but she also clung to the old ways of the family taking care of each other. She said many times, "I do not want to go to anyone's home," meaning us. She knew that we would not put her in a nursing home. And we knew, without saying, that she would die the same day she went in. She had all her faculties and the quality of care was in the back of our minds also. We knew that she would

get quality care at home among her own, and she would be happier and live longer.

Senator BRADLEY. What kind of services would have helped you?

Ms. BONGIOVANNI. More home health time. The cutbacks came gradually. At the end she was receiving 2 hours a day, 3 days a week. And it is very difficult, as Mr. Branagan stated, to meet all the needs, even if you are a female, because you are not a young girl anymore. And you have your own problems and your own families. We were raised to take care of our families in our own home, and suddenly they all had to cooperate, and they did. They all helped themselves to allow us to have the freedom to go and come. We spent 24 hours each under her roof, doing whatever came up, for a whole year.

Senator BRADLEY. Let me ask you, some people have suggested that private insurance companies offer policies for home health care. Is that the kind of thing that you would be interested in buying? Is that something that you would like to see the Federal Government provide incentives for senior citizens to purchase? Or should we deal with long-term care primarily through medicare?

Ms. BONGIOVANNI. I feel that it should be primarily through medicare.

Ms. RAPPAPORT. I agree with that.

Senator BRADLEY. You agree.

Mr. BRANAGAN. I would say so, too, inasmuch as originally I was against medicare. To me, I would rather have seen them raise social security, so that you could go out and buy private health insurance, because there would be less administration, more efficiency, and I think we would have been better off that way.

Senator BRADLEY. But now you would like to see medicare expanded?

Mr. BRANAGAN. Now, the way it is, certainly it would have to be expanded as it is now. The way it seems to me though is the cost of the medicare premiums are going up and the services are being cut down. I know my mother was not ready to come out of the hospital yet, but they discharged her and that is where I ran into the problem where I had to have help.

Senator BRADLEY. Ms. Thomas, do you have anything to say about what kind of services you think would be important to include in any home health care legislation?

Ms. THOMAS. Some of the patients I have had can afford to pay for it, and some cannot. So I would think it could be extended for those that need it.

Senator BRADLEY. But what services? We have heard from the panel that what is needed is to have someone in the home to make meals or just to be there. Five panel members are trying to live their life, and at the same time take care of their relatives. Sometimes it is difficult to be there all the hours in the day. And so the question is, how many hours a day of relief is needed, and what kinds of services do you find most helpful?

Ms. THOMAS. Well, they need to be bathed and some need to be fed their dinner. Some can handle it, and usually if there is a husband and wife, we teach one of them to help care for the other and to give them understanding and love. They do not want to leave. They are very happy. The homemaker goes in, and the patients are

very happy with the homemakers; they would much rather stay in their home than go to a nursing home.

Senator BRADLEY. Frank?

Mr. GERNE. Can anything be done about the pharmaceutical program? The cost of drugs seems to be going up all the time. One prescription of mine was $80 a month for my Parkinson's disease. Now my wife has an open leg that has to be taken care of and the tube of antibiotics ran $7.50, and that will last about a week.

Senator BRADLEY. The pharmaceutical assistance plan is at a State level.

Mr. GERNE. They allow $9,000 for one person and $15,000 for two persons. Now, why cannot that be $9,000 apiece, instead of the differential there? Pharmaceutical application.

Another thing I would like to ask is, why, since AARP insurance was taken over by the Prudential, are so many different plans coming into existence now? They are always writing you to increase your coverage? Why cannot that be stabilized?

Senator BRADLEY. I think that is a good point. We could come to that in the question and answer session, if you would like. What I want to do in this particular part of the hearing is hear from you. I will answer that question before the day is out for you, though.

Mr. GERNE. Thank you.

Senator BRADLEY. Would anyone on the panel like to make any further comment about the services that should be offered, anything that is particularly relevant to your individual circumstance that we have not heard? We have talked about the need for someone to come in and prepare meals, to bathe the person, essentially to be in the house. Beyond that, is there anything else; I think, Ann, you mentioned physical therapy.

Ms. CHARNOWITZ. Physical therapists, besides the homemaker.

Mr. GERNE. Why are there not more dental clinics that would work on the patient of medicare and medicaid?

Senator BRADLEY. Again, the dental plan and the pharmaceutical plan are separate from the specific issue of this hearing, which is long-term care in the home. Those are additional benefits. I will get to that. I basically think that you can increase them in some areas, but it is difficult when you are facing a budget deficit of $200 billion. But I think we can look at that though, later in the hearing.

I thank all of you very much. I am sorry. Mary, you wanted to say one more thing and I cut you off.

Ms. RAPPAPORT. I happen to be a nurse as well as a patient, and I think that medical care, physical care, is extremely important. But also we have to have an understanding of this person and how this person feels under the circumstances, and that is very hard for us to do.

I think there is a book out now, The 36-Hour Day. I do not know if you have heard of it. It comes from Johns Hopkins. And it discusses the homemaker who takes care of this person, and how important it is that we consider the caretaker as well as the person that is being taken care of, because that person needs help, too. Sometimes we forget that this person exists, and we think only of the person that is being cared for.

Senator BRADLEY. Thank you very much for your comment.

Ms. THOMAS. Senator, in my work, while we are working with a patient who we see needs a nurse, we will call the office, and the nurse comes in and evaluates the patient. If the patient needs further help, the nurse will tell us what to do. If they need physical therapy or speech therapy or whatever they need, we try to provide that. The people that we see tell us to have more understanding, to give them loving care, and so far as I know, we have been looked to as being helpful.

Senator BRADLEY. Let me thank the panel for your participation and your thoughts. I think that the panel gave very important personal testimony on the need for Federal legislation for long-term health care. I personally found your specific suggestions extremely helpful, and I hope that I will be able to convince my fellow Senators that the time for action is now, and that some of your suggestions could be actually included into law. Thank you very much for testifying today.

We have a second panel of witnesses, so if you all would like to have a seat one row back, we will call the second panel.

The second panel of witnesses are Anne Somers, who is a professor at the University of Medicine and Dentistry of New Jersey, Rutgers Medical School; William J. Kane, who is the medical director of Burlington Geriatrics Center; Winifred Livengood, director of Home Health Care Agency of New Jersey; Carole Kientz, who is assistant director of Christ Church Home Health Services of Jersey City; and Lois Forrest, who is executive director of Medford Leas Life Care Community, Medford, N.J.

I would like to welcome all of the panel members to the Aging Committee hearing and ask you to keep your statements to a few minutes. Maybe we will limit each of you to 4 or 5 minutes, and then get to questions. Welcome to the committee. Please make sure that you have a microphone so that everyone can hear you. We will start with Anne Somers, followed by Dr. Kane, Ms. Livengood, Ms. Forrest, and Carole Kientz. Thank you very much for coming. Anne Somers, you may begin.

STATEMENT OF PROF. ANNE R. SOMERS, DEPARTMENT OF ENVIRONMENTAL AND COMMUNITY MEDICINE AND DEPARTMENT OF FAMILY MEDICINE, UNIVERSITY OF MEDICINE AND DENTISTRY OF NEW JERSEY, RUTGERS MEDICAL SCHOOL, PRINCETON, N.J.

Ms. SOMERS. Thank you, Senator. I am a professor at the University of Medicine and Dentistry of New Jersey, Rutgers Medical School. For three decades I have been involved in the study and teaching of health care and health economics, with special emphasis on medicare and problems of the elderly.

I have strong personal, as well as professional, reasons for my interest in long-term care. My husband and I are both medicare enrollees. We have had a great deal of firsthand experience with the heartbreak of serious long-term disabilities and its catastrophic costs. We are not alone. Chronic disease is the most prevalent, the most urgent, and the most neglected area of U.S. health policy today. The tragic results of this neglect are evident in the plight of millions of frail and dependent elders, rejected by medicare be-

cause it does not apply to long-term illness, by medicaid because they are not quite destitute, and by most private health insurance, which generally follows the medicare benefit pattern. The irony is that despite this discrimination against chronic disease and disability, the cost of all of these programs continue to spiral upward. For example, while the ratio of medicare benefits to the overall health costs of the elderly has dropped to 40 percent or less, the costs of the program have climbed to an estimated $66 billion this year—about 2 percent of GNP.

Senator Bradley, for years you have been at the forefront of a handful of national leaders who are trying to come to grips with the very difficult problem of financing long-term care, not just for the relatively small number of the elderly who qualify for medicaid—about 13 percent nationally, about 5 percent in New Jersey—but for all those who truly need it. I salute you for your interest and foresight in this respect. As the number and proportion of elderly in New Jersey and the Nation continue to increase, year by year, I feel sure you will have no reason to regret your leadership in this respect.

In the few minutes I have available this morning, I thought the most useful thing that I could do would be to suggest five basic principles which could serve as guidelines as we move toward development of an effective long-term care program.

1. LONG-TERM CARE IS PART OF THE MAINSTREAM OF GOOD MEDICINE

The traditional approach to long-term care, as merely "custodial"—entirely separate from acute care, lacking in hope, undeserving of serious professional attention or mainstream financing—must be rejected. Ways must be found to integrate the long-term stroke patient, those with cancer, heart disease, multiple sclerosis, Parkinsons, crippling arthritis, Alzheimer's, and the long list of other severe chronic diseases, into a continuum with primary and acute care—fully deserving of professional interest and third-party financial support. The new field of geriatric medicine recognizes this—and deserves full public support and encouragement.

2. MAXIMUM FUNCTIONAL INDEPENDENCE AS GOAL

This should be the goal of all health care but is particularly important with respect to chronic disease or disability where, by definition, complete cure is impossible. But this does not mean that the patient cannot enjoy years of relatively active and productive life—often continuing in paid employment and paying taxes. The goal should be independence, not dependence. All policies should be directed toward this end.

3. MULTIDISCIPLINARY CARE CONSISTENT WITH MULTIFACTED PROBLEMS

The importance of a multidisciplinary approach is not unique to chronic illness but, in such cases, it is indispensable—due both to the length of time over which care may have to be sustained and to the variety of services required by the LTC patient. The usual physical diagnosis and medical management should be supplemented by functional assessment in which the nurse and/or social

worker play a part and by continuing case-management which focuses less on the patient's disabilities than on remaining abilities, especially in relation to the basic activities of daily living (ADL), and on the marshaling of available support services.

4. THIRD-PARTY FINANCING SUPPORTED BY MULTIPLE SOURCES OF REVENUE

Good long-term care will never be cheap. To the extent that the goal of maximum functional independence is substituted for the "custodial" approach it will become even more expensive. Third-party financing is just as essential to long-term care as to acute care. The fact that most patients with serious chronic disability are still expected to finance their long-term care completely on their own is primarily due to understandable historical factors which no longer prevail. Omission of long-term care benefits from medicare and most third-party coverage can no longer be tolerated and must be corrected. To spread the burden as painlessly as possible all reasonable sources of revenue should be tapped—not only payroll taxes, but general government revenues, special excise taxes (e.g., on tobacco and alcoholic beverages), premiums, and patient cost-sharing.

However, there are certain aspects of long-term care which indicate the need for more patient cost-sharing than is customary in acute care. Unmarried nursing home patients usually do not maintain a home and it would seem reasonable to devote at least part of such savings to the cost of their care. Families who are relieved of the burden of long-term care of a disabled family member should probably contribute to the cost of such care. However, it is essential to distinguish such limited cost-sharing from a means test directed at basic eligibility as is now the case under medicaid.

Incentives to efficiency must also be built into the program.

5. MAXIMUM PATIENT AUTONOMY

Autonomy—personal freedom and its corollary self-responsibility—is a quintessential aspect of functional independence and long-term care patients should be encouraged and helped to exercise the maximum autonomy of which they are capable. Generally speaking, this means preference for noninstitutional as opposed to institutional care, even in the case of terminal illness, although there will be many exceptions. Some patients will feel more secure if institutionalized. Others may require more continuous care than can reasonably be provided in the home. Ease of transfer from home to hospital or nursing home and back again is essential. Insofar as possible, preferences should be respected.

Autonomy applies not only to questions of settings but to modes of treatment, even to whether there should be treatment or not. This is the issue so clearly addressed by Chief Justice Hughes in the famous *Quinlan* case, where it was labeled the "right to privacy." The question of foregoing treatment is often difficult, especially in the case of incompetent patients. In such cases, institutional prognosis committees, as recommended in that case and now operative in most New Jersey hospitals, can be helpful to families, physicians, and third parties.

The translation of these five principles into public policy and an affordable third-party financing program will not be easy. But it can be done. S. 1244, the Bradley-Packwood bill, and S. 1614, the Heinz-Bradley bill, are both important steps in the evolution of U.S. policy in this area.

Elsewhere, I have suggested a proposal of my own which envisions eventual full incorporation of long-term care into medicare, with some special financial and administrative provisions.[1] Other countries—most of the Canadian provinces as well as the northern European countries, many poorer than the United States—already provide coverage for long-term care patients. We can too, and I am sure we will, once we really make up our minds that it is important.

Once again, Senator, thank you for your leadership.

Senator BRADLEY. Thank you. That was an excellent statement.

William Kane, welcome to the committee, again, and I look forward to hearing your statement.

STATEMENT OF DR. WILLIAM J. KANE, MEDICAL DIRECTOR, BURLINGTON GERIATRICS CENTER, MEMORIAL HOSPITAL OF BURLINGTON COUNTY, MOUNT HOLLY, N.J.

Dr. KANE. As Anne Somers indicated, I am a physician, I have a background in private practice in a rural town. I spent 7 years in academic medicine and currently work for a hospital corporation in southern New Jersey which is heavily involved in geriatric care. We currently operate nursing homes. We have an ambulatory assessment unit for the elderly and two primary care centers caring for a large elderly population. The corporation, a $70 million hospital and health corporation, has received very little help from a fragmented, disorganized reimbursement system, as we have tried to improve the care that 10,000 elderly receive in our system. That is the approximate number of medicare admissions per year.

It took 17 years for medicare to figure out that the incentives were completely wrong for hospital reimbursement. We have now gone to a prospective payment system, which clearly has changed life for a hospital corporation. We are trying to change with that medicare change, but we are running into a failure to appreciate that DRG's and prospective payment have a tremendous impact on long-term care, and there must be major changes in the reimbursement incentive system to change the priority of long-term care as well as acute care. To do one without the other is not going to work.

I would like to talk a little bit about the system. I would also, Senator, like to add my pleasure at your two bills, at least as an attempt to create a system and to look at incentives. We continue to have a series of services for the elderly. I am not at all sure that services in general are that deficient, but we certainly have no system of incentives to create the proper use of those services. We have an artificial and destructive reimbursement system in which we spend most of our time trying to find a way to pay for something that is truly needed.

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[1] Somers, A. R., Long-Term Care for the Elderly and Disabled: A New Health Priority. New England Journal of Medicine 307, July 22, 1982, pp. 221–226.

We have very little attention to true multidisciplinary assessment of need, and coordination is lacking. I would like to give you some examples of things that have happened to us.

You talk about medicare and medicaid and their ability to talk to each other. We acquired nursing homes in an attempt to change the nursing home into a much more proficient facility. Obviously, the cost might go up in the nursing home, but the system might save dollars. The answer from medicaid was we would just as soon have you not raise the cost in the nursing home and shift patients to the hospital for services that you plan to provide in the nursing home because medicare will pay the hospital bill and medicaid will pay the nursing home bill.

So, for the extent that $5 a day or perhaps $1,500 a year would change nursing home care, we are spending $3,000, $4,000, and $5,000 of medicare funds on an acute hospitalization.

No one has mentioned the fact that nursing homes are currently 90 percent proprietary or for profit. We do not think that is correct as a corporation and yet we are receiving very little help as a not-for-profit corporation to create a long-term care system.

Incentives currently are to utilize all services and agencies. And every agency spends a great deal of their time trying to maintain utilization. Clearly, if the financial incentive was created for all agencies and providers in the voluntary system not to utilize services except when needed, you might see some savings and services available to the truly needy.

In terms of the system, again, I think that the experiments that currently go on with the social HMO's are an attempt to provide those incentives to providers. And I firmly believe that there are tremendous savings, if we can get into prepayment and capitation. Anytime you are providing over 4,000 hospital days to 1,000 elderly people in the population, there has to be a way to lower that figure.

Senator BRADLEY. What is that number again?

Dr. KANE. There are 4,400 patient days of hospital care, acute care for every 1,000 elderly. That is medicare statistics, 4.4 days for every person in the United States. Most HMO's, at least one that I know of in Minneapolis, has cut that figure in half.

We have incorrect linkages and incorrect financial incentives. If you would allow providers such as us to have the funds that are currently spent, we will provide more care and better care by shifting funds from the hospital to other aspects of our health care system.

I would like to close by just making my usual plea as a physician. There are not many physicians who take care of elderly people as a full-time discipline.

Unless the Federal Government or somebody is going to provide some incentives to the medical education establishment, our progress will be too slow in the production of physicians who really understand the problems of the elderly. We have no strategy currently to produce those faculty. If you do not have faculty, you are not going to produce the next generation of physicians who must be much more knowledgeable than the last one in the problems of those people over the age of 75.

There is no standard of medical care which is acceptable for the elderly, much different than the standard of care which exists for children in this country or for surgical care or for obstetric care. We must have the medical profession lead the change in standards so we will no longer accept some of the things that are done to elderly in our hospitals and nursing homes in this country. This is not deliberate. It is just from a lack of experience and knowledge.

Finally, I just second Anne Somers' incentive, you must put long-term care in the mainstream of medical care. We must involve current providers. You must provide all levels of care. And you, above all, must provide incentives to shift funds from the hospital into other segments of health care for the elderly. Thank you.

Senator BRADLEY. Thank you very much, Dr. Kane. Winifred Livengood, welcome.

STATEMENT OF WINIFRED LIVENGOOD, PRINCETON, N.J., EXECUTIVE DIRECTOR, HOME HEALTH AGENCY ASSEMBLY OF NEW JERSEY

Ms. LIVENGOOD. Thank you, Senator Bradley. Good morning. I am Winifred Livengood, executive director of the Home Health Agency Assembly of New Jersey, which represents the 50 licensed and certified home health agencies throughout the State. As primary providers of home health services, under medicare and medicaid, we salute you and the Senate Aging Committee for holding this hearing on long-term care for elderly. Here the older citizens have had the opportunity to talk with you face to face to tell you of their needs and their anxieties. They have left us with not much to say in terms of what those needs are.

As providers, we see the elderly who are sick at home, many with chronic problems and limited resources to meet the demands of the disabilities. We see the families who care for them lovingly, sometimes grudgingly, often at great sacrifice or at peril to their own health.

I wish to assure you, Senator Bradley, that home health personnel have a deep commitment to health care patients and the family care givers coping with the trauma of illness, be it acute or chronic. The nurses, therapists and home health aides teach the patient and those helping him, that is, family, friend or neighbor, how to take the steps to function with independence. Their goal is to encourage self-help and at the same time to give the necessary care and support. In every county in this State, home health services are available, so then why am I here today?

Because there are great gaps in the medicare and medicaid programs. These gaps are a real impediment to giving care that is really needed. The families we helped have told you themselves about these Medicare limits.

Medicare is restricted to acute care only and needed services cannot be provided to persons with chronic health problems. Medicaid will provide chronic care, but only to that person whose income is under $312 a month. Many have not the funds to pay for service privately and there is no insurance, public or private, which covers the cost of long-term care for chronic illness.

Those with chronic illness will predictably have episodes of an acute nature. The goal of all health services must be to prevent or reduce acute episodes which require expensive hospital and medical care. Chronic conditions such as disabilities from stroke, or diabetes with its myriad of accompanying diagnoses, need ongoing supportive care and nursing management of this care. This will keep the patient stable and reduce acute episodes.

Too often permanent nursing home arrangements are made when home health services could have made the difference. The patient could have stayed at home. We agree with Professor Somers and Dr. Kane that it is time to make changes in our medicare-medicaid system.

The legislation you have proposed, the Senior Citizens Independent Community Care Act, should be enacted to let us find the best way to finance long-term home care. Our agencies know how to give the services and now we need to find out how to pay for them. Thank you for this opportunity.

Senator BRADLEY. Thank you very much, Ms. Livengood. Lois Forrest, welcome.

STATEMENT OF LOIS FORREST, EXECUTIVE DIRECTOR, MEDFORD LEAS LIFE CARE COMMUNITY, MEDFORD, N.J.

Ms. FORREST. Good morning, Senator Bradley, and the other participants in this meeting to consider the range of options that can best serve the needs of older adults.

One such option is called continuing care. I am the executive director of Medford Leas, a nonprofit continuing care retirement community, serving approximately 440 adults, ranging in age from 64 to 105, with an average age of 82. Each resident has a residence and care agreement that states that Medford Leas will provide all medical care, meals, housekeeping, laundry of linens, maintenance, community facilities, and transportation for shopping and banking.

The residents pay an entrance fee and monthly fee and have a choice of residential apartments ranging from a studio to two bedroom with den. We are located on 120 acres, and in addition to residential cottages, have a full range of licensed nursing areas, including sheltered care, intermediate A and B, and skilled nursing, with a complete outpatient department with radiology, ophthalmology, podiatry, and dental.

We have a waiting list of over 700 people. I think the most useful way to explain how the community functions is to give a brief history of one of our residents.

Ms. A is a 90-year-old, single retired schoolteacher. She moved into a studio apartment in February 1971 when she was 77 years old and paid a $15,000 entrance fee. This entrance fee is amortized over her expected life. She lived in her studio apartment and was a very active member of the community until she had a major illness when she was 84. As a result of that illness, she moved into an intermediate care nursing room and she continues to live there.

The residence and care agreement she has with Medford Leas provides for full medical care, prescription drugs, medical transportation, nursing care, physician charges, and hospital costs. Her monthly rate for her private room and all other care is $922 or

$12,270.80 a year. She has lived at Medford Leas for 156 months. If we divide her entrance fee by that number of months, the cost would be an additional $96 a month or a total of $1,018 a month.

She has the satisfaction of knowing she is able to pay her own way out of her small teacher's pension and social security, despite 6 years in a long-term care facility. Equally important, she has privacy, her own furniture and treasured possessions, broad and varied activities, and a physical plant with greenhouse, craft rooms, library, swimming pool, gardens, farm area and nature trail. She has a choice of menus, and although she is in a wheelchair, opportunities for trips, for shopping and picnics.

It is a community where there are over 70 resident committees, some of which she has served on, many opportunities for continued involvement, and contact with friends. Her life has dignity, opportunities for decisionmaking and security. She chose this community. It is her home. Had she not made this decision, it is likely that beginning in 1979, she would have begun to be subsidized by medicaid, sharing a small room, probably with institutionalized furniture, in a facility selected by someone else. The style of life she had previously experienced, in common with most of us, would have dramatically changed.

The needs for beauty, recreation, stimulation, decisionmaking, and privacy are important to us in later years, and we need to find and make available to older adults options with which they would be comfortable.

Continuing care retirement communities are rapidly growing and changing. There are two examples of developments in the field that I will cite to provide more understanding of its potential and possible future directions.

Within the past year, an organization called Continuing Care Accreditation Association was incorporated to provide an accrediting process similar to that available to hospitals, colleges, and private schools. The Continuing Care Accreditation Association examines all of the major functions of a continuing care community to determine if they should be accredited, and works with newly developing communities to help insure financial liability, full financial disclosure, and sound operating procedures.

Friends Services for the Aging was another organization also incorporated within the past year and has been funded by three major foundations to develop a lower cost model of continuing care. One model being considered is a geographically dispersed concept similar to an HMO. I might note to the group today that Senator Bradley is a member of the advisory committee for Friends Services for the Aging.

This concept of shared expenses and a broad range of services over the senior years of the life of the participant has great potential for meeting the varying lifestyle, economic and physical needs of older adults, while decreasing the need for Federal or State medicaid subsidies. Much attention is being directed to the high cost of medicaid and medicare, without considering severe problems faced by many adults when they need long-term care. I would urge that attention be given to the requirements of the frail, acutely ill, or mentally impaired adults, many of whom do not have families available to provide care, even if assistance was available.

Thank you very much for this opportunity.

Senator BRADLEY. Thank you. Carol Kientz.

STATEMENT OF CAROL KIENTZ, ASSISTANT DIRECTOR, CHRIST CHURCH HOME HEALTH SERVICES, JERSEY CITY, N.J.

Ms. KIENTZ. Thank you, Senator. I feel as though I will bring these testimonies a bit to full circle because I am going to go back to talk about some of the things that the patients and family members themselves addressed earlier this morning.

I am a public health nurse with Christ Hospital's home health services division, which is a New Jersey State certified home health agency. And I have been visiting patients and families at home for almost 20 years now, and the problems really have not changed. They have just gotten worse, because we have more elderly at home with us now. The problems are emotional, social and financial, but I have tried to pick just a couple of the families that we have been visiting recently, that I think exemplify the situation and the difficulty for home care agencies.

And I think I need to put in one little plea, too, or at least a statement that we, as visiting nurses, are usually the first people and the ones with the responsibility to go to families and say "medicare will no longer pay for this. The services are going to be reduced or terminated." And it is probably the most difficult responsibility that a visiting nurse has, but we have it and we live with it every day.

Let me just tell you a little bit about Mr. M. He is an 81-year-old gentleman here in Jersey City with chronic leukemia. He also has heart disease and arthritis. His wife died a year and a half ago. She was of some help to him until she died. In truth, they were helping take care of each other. They have two children but they live out of State and several States away.

He is now extremely weak. He cannot leave his apartment. He can manage to walk around on a good day and at least get by in his apartment, but he needs help to do simple chores. He needs help to fix his meals. He needs help to give himself a good bath.

Until recently, none of these services were covered by medicare, but he was one of the fortunate elderly who qualified for medicaid until recently. His income went up a little bit at the beginning of 1984. Now he has about $670 a month coming into him. He is no longer qualified, therefore, for Medicaid, because he has a little bit too much income, so it left him with nothing. So the visiting nurse has the responsibility and certainly the obligation to try to find some other resources for people in this situation.

We helped him get on the waiting list for title XX, but as one of the witnesses said earlier this morning, there is a waiting list, and sometimes that waiting list goes until the end of the year until funding is available at the beginning of the next year. He is also on the waiting list for Meals-on-Wheels. It is a much shorter waiting list, but nevertheless the funding is short. Even when he gets on Meals-on-Wheels, that is only one meal a day, 5 days a week. It is not enough to survive on, certainly. So the hospital is actually giving him some free help a couple of days a week, and another program that has been very beneficial, the Senior Companion pro-

gram, is helping out 2 days a week, with a senior citizen who is visiting a couple of hours each of those days to help out with the little chores and the grocery shopping and so on.

We wish we had more senior companions, but in an urban area, it is hard to find an elderly person who is physically able to go and help another elderly person. But certainly we could not do without that program as it stands. And, fortunately, he has a few friends in his apartment building who look in on him over the weekend, because there is often very little, if any, help available through agencies and other resources on the weekends. That is a very typical situation.

Moving down, because I really feel a strong need to put in a plea for somebody that is not a senior citizen, but exemplifies a problem we at home care have, and she will become a senior citizen and the problem will still be with us, but worse, is the woman with multiple sclerosis. Most of these ancillary services, Senior Companion, title XX, a senior care program, which our local visiting homemakers has, which is excellent—these require that you be a senior citizen, just being disabled is not good enough. But someone in their 40's or 50's with multiple sclerosis who is bedbound, cannot walk, can barely speak in some cases, cannot feed themselves, they need as much help as anybody, but their care is chronic.

They may have medicare, because they have been disabled long enough to have medicare, but medicare will not pay for chronic care, so they do not have that. We called the Multiple Sclerosis Association. They do not get enough donations anymore to pay for any help at home. They will help with wheel chairs and equipment, but people do not donate as much because they think medicare is helping, so we cannot get help through that organization. We cannot get title XX because she is not a senior citizen yet. We cannot get much of anything, except crying for free care from anyplace that is willing to donate a little money.

This one woman does have a husband, who is disabled himself, both emotionally and physically. By the time they are senior citizens, I suspect their marriage will not exist, and I do not know if physically one or the other of them may not be further damaged.

We have a senior citizen couple right now, too, in which the wife also is the person with multiple sclerosis. They are both in their 70's. The husband has heart disease and has been advised not to walk up and down stairs or do any strenuous activity. They are a little luckier because she has not been able to bladder train herself. That means she has to have a catheter to drain her bladder. Therefore, medicare will pay for some help, almost indefinitely, hopefully, until those regulations change, too, which could happen any day. But we can give them help 3 days a week in the form of an aide, as well as a registered nurse, to help care for the catheter and supervise their needs, and give some family counseling to the couple, because this couple had been honest and said, we really fear physical violence against each other, this is so frustrating and so difficult to survive for years and years with this kind of problem to care for.

The younger woman was smarter and worse off because she taught herself, she bladder trained herself with the help of nurses and physicians and does not need a catheter. Therefore medicare's

regulations say that she has no skilled care need. She is chronic. She gets nothing. A simple rubber tube can make a difference. And that is the way medicare's regulations are written, and we have no choice but to abide by them.

Just to wrap up with another example of the frustration that the elderly face, and these are the people who really I think have difficulty in coming here and even voicing the problems in public because in private it is even hard for them to admit to themselves what is going on.

Mr. D is a 69-year-old man who is severely disabled from several strokes. He has been in bed for a couple of years now. Requires complete care, feeding, toileting, bathing. He, too, requires that rubber tube, that catheter, so we can give him some help under medicare indefinitely. But his wife, who is also caring for a retarded son, an adult-age son who is severely retarded, is so frustrated that in truth there are days when her husband goes without care. If the aide is not there, he may not get toileted. He may not get fed. When the aide comes in on Monday, the weekend was obviously a disaster. And he is lying in his bed showing the results of a disaster.

A nursing home might be an option, but without his social security check, his wife says she cannot manage, so there is absolutely no way that she will consider a nursing home. So we go on trying to help them manage with their frustrations and provide counseling as well as care to both of them.

These are typical situations. I could have picked, and any nurse in home care could have picked from hundreds. The answers are difficult. We know that medicare is running dry. But we hope that at least other community resources like Meals-on-Wheels, Senior Companion, title XX services, any variety, medicaid and the expansion of it, to meet the needs of the elderly at home rather than in nursing homes, that all of these might be expanded in some way to meet some of these needs. Thank you.

Senator BRADLEY. Thank you. Let me thank the panel for your testimony. I think that it will be of real value to the committee's deliberations on this issue. And I would like to ask just a few questions.

Two general questions and then I would like to ask each of you specific questions.

First, you cannot be precise, but could you estimate from your own experience what percent of the people who are in nursing homes would prefer to be in their own homes? Does anyone want to take a crack at that? Dr. Kane.

Dr. KANE. A high percentage. I think you have to separate some things when you talk about nursing homes versus the alternatives. And someone said earlier, a nursing home is not always a bad choice. And there are some elderly who perhaps were so scared and so frightened at being alone, perhaps welcome being in a nursing home setting in terms that it is safer and easier for them. So not everybody that is there, necessarily wants to be outside the nursing home.

I think the question then can be broken down into a number of people in the nursing homes are probably not competent to make that decision. And then of the ones that are competent to make

that decision and have an alternative and were not that disabled, I think would rather be outside the nursing home setting.

As long as we allow the situation to go on where you can get into a nursing home by several routes, the utilization of nursing homes will grow. If I have money right now, I can get into a nursing home anywhere in the United States, and I could just sit there long enough to spend down my resources, and by the time that spend down has occurred, the resources in the community and the support systems have deteriorated and the person is in the nursing home forever at public expense.

The other statistic that is very clear from numerous studies is that 25 percent of the people in the nursing homes clearly do not need to be there. They were there for a multitude of reasons, mostly this artificial, financial system that currently exists.

Senator BRADLEY. So you are saying that 25 percent of the people who are in nursing homes, should not be in nursing homes for a variety of reasons?

Dr. KANE. I would say that. I want to emphasize again what I said in my testimony about nursing homes being a proprietary operation for the most part. Not necessarily the ones that you heard from today. And I do not claim that those are bad people or bad nursing homes, but they have absolutely no incentive not to admit the least disabled person and to discharge someone. There is no incentive. What you do in a proprietary nursing home is you want to make as much profit as you can. You would like to have the least disabled person available to you. And you would like to keep them in that bed because when the bed is empty, you do not get any income.

The difference in a system like ours, which is a hospital system, is we are trying to keep people from being kept in the hospital, so we want another level of care, so that then we are interested in keeping our nursing home active and increasing discharge. And what is happening now is that no nursing home is taking the types of patients that are being discharged under DRG's because they are incapable of taking care of them, and they do not get anymore reimbursement from medicaid or from medicare, for that matter, for taking care of someone that has severe disability versus practically no disability. Until somebody recognizes those incentives for the types of patients that should be in nursing homes, then all of us are going to be flailing around in a system that is artificial and disconnected from the mainstream of medical care.

Senator BRADLEY. So you are saying that the incentives that are there now essentially discourage nursing homes from taking the most disabled.

Dr. KANE. Absolutely. And they also discourage anyone from attempting to get someone out of a nursing home, as long as there is some way to pay for it, that is, we can sit here long enough that Medicaid will have to pay the bill.

Senator BRADLEY. And your suggestion is what?

Dr. KANE. My suggestion is, one, to get into a situation where you can encourage some balance in nursing homes between strictly proprietary or those belonging to a system that has other levels of care under their control. I am also urging someone to get into the prospective payment business in the nursing home and in long-

term care, so that simplistically someone is given a set amount of money to deliver care, and I will guarantee that it is delivered cheaper and better than it is now with all the artificial barriers that are set up.

Senator BRADLEY. Are you saying that what is absent now is a the third-party payment mechanism for someone who would try to meet that need of long-term care?

Dr. KANE. You run into the same regulations that everyone here today has been talking about, artificial regulations which do not deal with the practical problem at hand. And they urge you to disable somebody, is what they really do.

Senator BRADLEY. Ms. Somers.

Ms. SOMERS. Senator, as I said in my testimony, I think there is no question, the majority of people in nursing homes would prefer to be at home, if they had a home and if that was possible. But we have to keep in mind a fact which came out today also, that there is going to be a fairly significant minority for whom that will not be feasible. They either do not have a home, or they do not have children, or they do not have a spouse, or there may even be abuse. That has already been intimated. There are some things worse than being in a nursing home. To be totally isolated or to be the victim of family abuse, is worse.

Senator BRADLEY. I did a town meeting not so long ago, and a person stood up and said that if you are discharged early, by a hospital, and then you go home, and in a home setting you have a family that wants to care of you, the family does try to care for you, but at some point they have a limit, too. At some point they become emotionally distressed, and sometimes they end up abusing the senior citizen. Do any of you have any evidence of that in your own experience or could you comment on that?

Ms. SOMERS. I was surprised that respite care was not mentioned, in the first panel. That is included in your bill. And it is terribly important. There are various ways it can be taken care of—by having the patient moved into a nursing home, say for 2 weeks once a year, or having people come into the home and let the caretaker go off on a vacation for 2 weeks, or maybe 2 weeks plus 1 day each week. That could make all the difference. This has been done in some places in England with very, very good results.

One other thing I wanted to say is that it is not all either/or between nursing home care and home care. One of the beauties of the continuing care or life care community is that it permits transitions. People remain, as long as possible, in their own apartments, their own little homes, but they are in a sheltered environment which promotes a sense of security. I have just joined the same committee that Lois Forrest mentioned earlier, the advisory committee that you are on. This is one of the most exciting things going on today—the development of a new modality, somewhere between total independence, which not many people can maintain at 90, and total institutionalization.

Senator BRADLEY. Let me ask Ms. Livengood, if I could, do you find that your home health aides generally go to the homes of senior citizens who have no family or to the homes of senior citizens who have families that have a multitude of demands on their time and therefore need assistance to keep the family together?

Ms. LIVENGOOD. I think they go to both. There is no question about it. Their caseloads reflect both. There obviously needs to be greater help for that person living alone than for those that have family members, but again we have that whole question of burnouts, they call it, and the need for respite care. So I do not think it is the living alone for at least on short terms that is the determining factor for long-term, and with no long term care payment source, they are the ones that have to go into a nursing home.

I would like to make another comment on that nursing home issue. The data is very interesting on the SNF's, the skilled nursing facility, which is a medicare benefit in a nursing home, and home health. For the past number of years, the use of home health has far outstripped the use of the SNF. I think this shows there are people who choose to go home, and also that SNF's are not willing to take patients requiring a high level of care. We think that the patients that are coming home now under DRG's are sicker than any patient that is going into a nursing home. This is the reverse of what you think would be happening.

Senator BRADLEY. So you are saying that given the DRG's there is a real need for skilled nursing homes, hospital-based skilled nursing homes?

Ms. LIVENGOOD. Well, I really think we are taking care of the skilled nursing patient under the medicare program at home; people have chosen to go home rather than into a nursing home or the nursing home has refused to admit someone that needed that much skilled care.

Senator BRADLEY. Well, you might want to know, if you did not, that we have achieved a victory on the question of reimbursement for hospital based skilled nursing home facility; we have finally gotten the law to be implemented, which means a higher rate for hospital based skilled nursing homes.

Ms. LIVENGOOD. I had not heard that. That is good news.

Dr. KANE. For medicare only, which is only 9 to 13 percent, depending on the nursing home. So what you are really talking about is medicaid. The loser in the nursing home right now is the private pay patient, because that cost is being shifted. Medicaid is actually paying less than the cost of operating a nursing home.

Senator BRADLEY. And then the private patient ends up paying more. Until they spend down.

Ms. LIVENGOOD. Yes. Right.

Dr. KANE. All I am arguing for is put the provider at risk, Senator, so that providers have a financial risk if they do not find the cheapest way to deliver care. And if that can be done continually across this country through capitation, through other incentives, then the provider will always find, with the right incentive, the cheaper way to provide care.

Senator BRADLEY. Let me ask a general question. Did you want to make a comment?

Ms. FORREST. Well, I wanted to go back to your question about how many people in nursing homes do not need to be there. The fastest growing part of the population in our country today is the group over age 85. They tend to be the group who are most likely to need extensive care. What we have seen in New Jersey is there was a time 5, 10, 15 years ago, when there were many people in

nursing homes that probably did not need to be there. There are far less today. And the point made earlier is that many of the people needing nursing homes have very extensive medical needs that could be better met in nursing homes. If nursing homes could raise their level of care, people would be better served there than in a hospital, where it becomes extraordinarily expensive with all the high technology that is there.

So I think that I would suggest if we use a DRG system for nursing homes, that would mean that even nursing homes that were not part of the hospital system could be paid for patients who are receiving tube feedings, intravenous care, as well as incontinency and other kinds of problems, and they can be handled in long-term care.

Senator BRADLEY. Let me, if I could, as we head toward the end of this session, try to get you to focus on cost. We have a medicare system that is providing a whole series of services. That system is financially very tight right now. Yet all of you have reemphasized the need for additional services, including home health care, long-term care. I am curious as to how you see this being financed, given the financial problems with the medicare system. Have you given any thought as to whether any pressures would be generated between long-term care and the existing medicare system.

That is a big question. That is what Senate hearings are for, to ask you the big questions.

Dr. KANE. The issue of cost is very simple. We afford everything but the least expensive. I can put anybody in the hospital who is over 65 tomorrow for almost anything. I can give you examples of the previous owners of our nursing home having no capability to provide certain services, but a relative owned the ambulance company, and patients could be transferred everywhere they had to be at medicare expense with the ambulance. I can give you numerous examples of hospitalization for problems capable of being cared for in the nursing home.

Simply stated, Senator, you must find the way to get the dollars out of hospital system and for every dollar you get out of the hospital, if you cut admissions in half in one of these demonstration projects, you have saved thousands and thousands of dollars, which leaves funds for other services in other settings.

I also have to say one other thing that has not been said today, and that is the issue of assessment. And assessment in this country. We are not assessing needs right, we are assessing demand. And there is a big difference between need and demand.

Senator BRADLEY. Could you talk about that a little bit?

Dr. KANE. My concern about assessment is that everybody does it. In Burlington County, I bet there are four different agencies. Medicaid has theirs, and then they have their waiver, and then medicare does their thing, and then somebody else comes in and assesses. Patients are all different. The assessment has to be multidisciplinary, but it has to be very skillful and you cannot have back doors around it. You cannot have an assessment that says for the medicaid patient you have to have less than $312 a month for services, and then have someone who happens to have a little bit of money enter a nursing home, take the next bed, when they can pay for the first year and then get on medicaid anyway. There must be

a uniform assessment in every community, which says that this person, regardless of who they are, what their ability to pay is, who their family is, and who their advocate is, gets the same services based on need.

Senator BRADLEY. So you are essentially saying that through greater efficiency in the hospital system, which implies fewer admissions or shorter stays, the revenue that that would be freed up could be used for longer term home health care?

Dr. KANE. That is correct. And it also says that that we must get rid of the artificial separation between long-term care services and hospital services.

Senator BRADLEY. As a physician, you give us an unusual perspective. What can you say to senior citizens who themselves are concerned that there be quality care, and who are worried about a system that puts in these kinds of incentives? What can you say to reassure them about incentives not affecting quality of care?

Dr. KANE. The only issue I can bring up, Senator, for the critics of DRG, which I am not one, and in fact travel around the country convincing medical staffs that DRG's are the way of the future, so conceptually I agree with it. I may have some problems with how hard that is pushed when its major reason right now is to cut the bottom line.

The issue that elderly have to recognize is that not all medical care provided to them is in their best interest. And that in fact, if you look at numerous studies of hospital care, including one published out of Boston recently, you are seeing numbers like 40 to 45 percent of admitted patients have an unfortunate event in the hospital. I have spoken many times and people in this audience have probably heard me be critical of hospital care of the elderly. I do not believe we do it well. I do not believe that we have recognized the fact that elderly are so different that they should not be on a regular medical-surgical floor. But until we recognize that not all hospital care is good for elderly, we will continue to admit unnecessarily.

So in answer to your question, DRG's will provide an incentive. They will lower the incidence of admission. They will shorten hospital stays. That is clear from the New Jersey experience. That is a good thing. I do not believe that people are being discharged before they are ready. But to assure proper discharges, there must be other levels of care and assistance to take care of the elderly. I think that the elderly will find that if that system could use the savings from the hospital side, that you in fact will see better care for the elderly than you do now.

Senator BRADLEY. Would anyone like to address the cost issue? I think you did a little bit in your opening statement, Ms. Somers.

Ms. SOMERS. Well, I would just add a couple of words. It is generally recognized that about 10 percent of hospital days today are consumed by patients who are "backed up," simply waiting, for appropriate discharge. The hospital wants to get rid of them. The doctor is ready to discharge them. There is no place for them to go—either home or to a nursing home.

There was a story in the New York Times last fall, of a woman in Long Island Jewish Hospital in New York with a stroke. She had been waiting for at least 6 months. It was costing $400 a day

and there were 30 nursing homes on Long Island which had turned her down. There was just no place for her to go. They were not able to take care of her at home.

Ten percent of whatever medicare is spending just for hospitals—$45 billion or so—is a lot of money, and that is very important.

We also have to look for more sources of revenue, as I indicated before. The recent report from the Advisory Council on Social Security suggested that we look to excise taxes on tobacco and alcoholic beverages as a new source of revenue. That certainly seems sensible to me. I have also suggested that if you added just $1 a month to the part B premiums of older people who smoke—I don't think anybody knows exactly how many there are, but let us say it is 10 percent—you would raise $36 million a year right there.

There are other ways of increasing revenues. In terms of patient cost-sharing and the question you raised about the attitude of many senior citizens. If the tradeoff for some reasonable cost-sharing on the 2d to the 59th or 60th day, if the tradeoff for that were real catastrophic coverage—not the misleading idea which has been proposed recently, just for mere in-hospital benefits for that one-half of 1 percent that stay in the hospital longer than 60 days—which would include long-term care and nursing home care, then I think there would be serious interest on the part of most senior citizens. There is room for a lot of creative financing in this area.

Senator BRADLEY. Thank you. Ms. Forrest.

Ms. FORREST. Three things very quickly. Earlier Dr. Kane mentioned social HMO's. I believe they are having trouble getting waivers now in order to go forward with their demonstration projects. And I think we need to see more demonstrations done over a period of 3 or 4 years, such as your bill, to see what can and cannot work and how they need to be adjusted.

Second of all, I think there needs to be better case management in the hospital. I think this follows up on what Dr. Kane is saying. Recently a woman I know who is in her 80's ran a stoplight and her car was hit by a truck. When she went into the hospital, she said, "I blacked out." She didn't black out. She was hit by a truck. But for 1 week the doctors looked for what made her blackout.

Had there been somebody following up on that case from the beginning, they would have known that. They would have told the doctors. It was very clear information that her family had, the police had. I think we need to have better case management.

I think that people will pay for insurance or some kind of a plan that is a cost-sharing plan. We have the group that we have been hearing a good deal about, who do not have funds to be able to pay for some kind of insurance. But we also have a good many Americans who own their own homes, have social security, and another pension fund. They cannot pay for years and years of long-term care because they then run out of money, but if they share it, and as they do in a continuing care model and can be developed in similar models, developed in different ways, then I do think you will find a great many senior citizens who would like to provide for themselves some form of catastrophic insurance that deals with home care or long-term care.

Senator BRADLEY. Dr. Kane.

Dr. KANE. One comment about the Health Care Coordination Act and who is going to administer some of the demonstration projects. And I just want to put a plug in for trying to convince some of the waivers and some of this to be given to some of these larger HMO's in the country. My example would be to try to entice in this part of the country a company like U.S. Health Care Systems, which is the fastest growing and one of the most successful HMO's in the country and has the expertise to put everything together. I do not want to criticize States, but I think that in some of these demonstrations, I would hate to see them completely involved in the State government and the State bureaucracy, and I would like to see some of the demonstrations go into the private sector. Some of the bigger companies could be enticed to take those medicare dollars and see if in fact they could make them work better than the States could make them work.

Ms. LIVENGOOD. I would go for that. We have a medicaid waiver in New Jersey which is very involved and administered by the State government. Cost-sharing is required of the client and the State is finding a tremendous reluctance on the part of the client to do cost-sharing. Of all the impediments they have come across in the first 5 months of that plan, cost-sharing has been the most serious.

Now, you are dealing there with a population, a large population that is just above the medicaid income level. And I think, if anything today, it shows the variety of options that must be open because there is money on one hand to pay for some of the care and on the other there is absolutely no money to pay. We do not want to ever develop two levels of health care in this country, so that those who cannot afford to pay for an elaborate insurance plan have a lesser quality and less accessible health coverage. I think the great dangers that we see in all these plans is the potential for two levels of care.

The other thing I would like to say in answer to the cost of it. Home health, for the 16 years under medicare, has been really the stepchild. It has been the object of many studies, all of which have said we have no way to control the costs, we do not have any data, it will just be an add-on. And we are up to here with hearing that.

And I think your bill, the sooner we can get that going with a demonstration, plus the HCFA demonstrations on prospective reimbursements, certainly are in the right direction. And I agree with Dr. Kane that there must be some incentive to convert the moneys that are reduced from hospital stays into home care. We really look to you for the leadership to stop nonsense about it just being an add-on cost.

Senator BRADLEY. Well, that is what I have been asserting for a few years and hopefully we will have that chance.

Let me thank you all for your participation in today's hearing. I personally found what you had to say extremely interesting and I think very helpful. It will give me a little more information and a little more ammunition as I continue to press for the passage of these long-term home health care bills, so I want to thank all of you very much for coming and testifying.

The hearing has concluded.

Now, I said to a number of you in the audience, although the hearing is concluded officially, if you wanted, at some point, to make some comments, you may do so.

[Whereupon the hearing was adjourned 12:45 p.m.]

APPENDIX

STATEMENTS SUBMITTED BY THE HEARING AUDIENCE

During the course of the hearing, a form was made available by the committee to those attending who wished to make suggestions and recommendations but were unable to testify because of time limitations. The form read as follows:

DEAR SENATOR BRADLEY: If there had been time for everyone to speak at the hearing on "Meeting the Present and Future Needs for Long-Term Care," in Jersey City, N.J., on February 27, 1984, I would have said:

[The following replies were received:]

RUTH BERNSTEIN, BAYONNE, N.J.

Many services, such as visiting nurses and aides, are only available 5 days a week, or less; please consider services to be planned on a 7-day week, and more hours per day.

Senior citizens housing should be expanded to include medical assistance within each building.

RACHEL S. BIRCHETT, JERSEY CITY, N.J.

My first statement will be: There is a dire need for dealing with preventive methods to offset the hearing loss by seniors.

There should be an ongoing encouragement for younger citizens to supply information in these areas. The younger the mind the more creative thinking is generated. The senior citizen program should be staffed and paid for just as the teaching profession, police, and all other public assistance personnel.

Young people beware. You will some day become "one," so prepare for a better future "now."

SISTER NORAH CLARKE, M.S.W., JERSEY CITY, N.J.

I would discuss alternatives to long-term nursing home care:

(1) Congregate services. In New Jersey, it is proving to be a cost effective delay tactic to institutionalization.

(2) Improved support services. The margin of eligibility for services under medicare is unrealistic. Persons in need are expected to pay for services which they can't afford.

(3) Stress need for education of the "young old" in terms of biological aspects of aging (i.e., nutrition) and psychological aspects (i.e., role change/role adaptations).

Should there be another opportunity in the State where I could comment for the record, I would welcome the chance.

Time permitting, I may write to explain what I see happening in public housing among the elderly. The testimony today was from people who represent a much higher economic background than the people with whom I work.

SISTER VIRGINIA KEANE, JERSEY CITY, N.J.

Senator Bradley raised the question of abused elderly that no one on the panel answered.

Legal Protective Services for the Elderly have very limited resources to deal with such an extensive problem.

The elderly who become incompetent mentally and/or physically are among the most neglected (and abused) of our society.

JAMES MORREALE, BAYONNE, N.J.

"The dignity of the individual" is still part of the American doctrine. After hearing the first panel of witnesses, I feel that a sad and indecent state of affairs exists for the aged in this country. How sad—how outrageous. We are almost 27 million strong—we should let our anger be heard at the polls. Political activity is called for—"Throw the bums out."

JOHN W. THOMAS, JERSEY CITY, N.J.

Directed to Senator Bradley:

Sir, you asked how the services proposed by the panels this morning could be financed under medicare.

I feel, if part of the moneys being sent all over the world, and this amounts to billions, could be administered through medicare, it would be better appreciated by those in need at home in the good old U.S.A.

Further, if the Senate and House would check on M.D.'s and hospitals, the cost might be considerably reduced.

WILMA WEISS, R.N., JERSEY CITY, N.J.

I represent Visiting Homemaker Service of Heed Co. As a board member, I was a former employee as R.N. They have a waiting list at present of over 200 people on title XX, and senior care programs. Patients can be maintained in their homes for a long time with some part-time services at home which is much cheaper than nursing home placement.

I left employment to care for my 94-year-old parent who lives alone and is maintained by me plus a visiting homemaker three times a week for 4 hours (on medicaid), which is some respite for me. I do not feel that I would be able to go on if it was not for this care. My husband and I were also responsible for his parents and the visiting homemaker helped us survive those problems.

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